

Considering Care-Seeking Behaviors Reveals Important Differences Among HIV-Positive Women Not Engaged in Care: Implications for Intervention

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Abstract

We sought to examine characteristics of HIV-positive women with varying levels of engagement in care and care-seeking behaviors. From 2010 to 2013, in a multi-site US-based study of engagement in care among HIV-positive women, we conducted baseline interviews, which included socio-demographic, clinical, and risk behavior characteristics, and barriers to care. We used multinomial logistic regression to compare differences among three distinct categories of 748 women: engaged in care; not engaged in care, but seeking care (“seekers”); and not engaged in care and not seeking care (“non-seekers”). Compared with women in care, seekers were more likely to be uninsured and to report fair or poor health status. In contrast, non-seekers were not only more likely to be uninsured, but, also, to report current high-risk drug use and sexual behaviors, and less likely to report transportation as a barrier to care. Examining care-seeking behaviors among HIV-positive women not engaged in care revealed important differences in high-risk behaviors. Because non-seekers represent a particularly vulnerable population of women who are not engaged in care, interventions targeting this population likely need to address drug use and be community-based given their limited interaction with the health care system.

Introduction

MANY WOMEN LIVING WITH HIV in the United States (US) face substantial challenges to engaging in HIV medical care.^{1,2} Only 40% of HIV-positive women are engaged in ongoing HIV care (e.g., regular visits with an HIV medical care provider) and merely one-quarter of HIV-positive women are virally suppressed.³ As a result, many are not receiving the full benefits of HIV treatment. Consequently, they are at high risk for poor health outcomes and for transmitting HIV to others.^{4–10}

Although prior studies have identified numerous factors associated with poor engagement in care (e.g., lack of transportation^{11–13} and health insurance,^{14–19} caregiving responsibilities,^{13,20} depression,^{13,16,21} and substance use^{14,16,19,21–25}), these studies have been limited in two important respects. First, many have viewed those who are not engaged in care as a single, homogenous group, failing to recognize potentially nuanced

differences among women that may help to inform the development of targeted interventions. Second, these studies have not routinely taken into account care-seeking behaviors among those who are not engaged in care. Care-seeking behaviors are a significant determinant of health care utilization²⁶ and, therefore, vital to consider when attempting to understand potential differences among individuals not engaged in care. Specifically, there may be differences in characteristics and barriers to HIV medical care among those who are not engaged in care, but who may be actively seeking care as compared with those who are not engaged in care and *not* seeking care. The latter group may be at greater risk for poor health outcomes, as they are probably less likely to interface with the health care system and, therefore, have fewer opportunities to receive care.

Currently, there are only two published, rigorously evaluated interventions focused on retaining women in HIV medical care in the US.²⁷ Therefore, understanding differences that may exist among HIV-positive women who are not

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engaged in care, by taking into account care-seeking behavior, may be helpful in the development of future interventions. Therefore, as has been traditionally done, we first examined differences between women engaged in care and those not engaged in care. To explore additional potential differences that may be targets for tailored interventions, we then compared three distinct categories of women, which take care-seeking behaviors into account: women engaged in care; women not engaged in care, but seeking care; and women not engaged in care and *not* seeking care.

Methods

Setting

We used baseline data from the Evaluation and Technical Assistance Center (ETAC) funded under the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) Initiative—Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color. The nine sites involved in the HRSA SPNS Initiative are discussed in detail elsewhere.²⁸

Participants

From November 2010 to July 2013, participants were enrolled in the study. Eligible participants were: (1) 18 years of age or older; (2) HIV-infected; (3) a woman of color; and (4) in one of the following categories: new to care (no previous clinical encounter at the study site), sporadic care (one visit in the last 12 months at the site), and lost to care (no visit to the site in the last 12 months, but one visit in 12 months prior to the last year).²⁸ Although the Initiative included women who were newly diagnosed, because our focus was on engagement in ongoing HIV medical care, women diagnosed less than 3 months prior to baseline interviews were not included in this analysis. Given the diversity of sites (e.g., one site recruited predominantly homeless women from the streets, another site recruited from an Infectious Diseases clinic), a variety of recruitment strategies were utilized including community outreach, health care provider referrals, and approaching potential participants at HIV testing programs. Written informed consent was obtained from all participants.

Data collection methods

The questionnaire was developed in collaboration with the study sites and included 206 items from novel and existing standardized instruments. The questionnaire included questions about socio-demographic characteristics; drug use and sexual risk behaviors; self-assessed health status and health history;²⁹ domestic violence;³⁰ HIV medical care history; and structural barriers to HIV medical care. Interviews were conducted in English or Spanish in a private room by site staff and lasted 40–90 min. Staff at all sites underwent standardized training (in person as well as via webinars) in conducting interviews.

Dependent variable of interest

Our dependent variable of interest was care status. We categorized participants' care status in two ways: (1) engaged in care/not engaged in care ("traditional" categorization) and (2) engaged in care/not engaged in care, but seeking care/not engaged in care and not seeking care ("nuanced" categorization).

Our categorization was based on participants' responses to the following question: "Which of these statements best describes your current situation, in terms of looking for HIV medical care?" (a) "I have been receiving HIV medical care in the past 6 months prior to today," (b) "I have tried to get HIV medical care in the past 6 months, but am still waiting to obtain HIV medical care," (c) "I have not yet tried to get HIV medical care in the past 6 months, but may do so in the future," (d) "I am not considering seeking HIV medical care at this time." In the traditional categorization, those who selected (a) were categorized as engaged in care ("in care"), while all others were categorized as not engaged in care ("out of care"). In our nuanced categorization, those who selected (a) were categorized as engaged in care ("in care"), those who selected (b) were categorized as not engaged in care, but seeking care ("seekers"), and those who selected (c) or (d) were categorized as not engaged in care and not seeking care ("non-seekers").

Independent variables

Socio-demographic variables were age (<30, 30–50, >50 years old); race/ethnicity (non-Hispanic black/African American, Hispanic, other); primary language (English, Spanish, other); marital status (single, married/partnered); level of education completed (less than high school, high school or higher); employment status (employed, not employed); geographic location (urban, rural); primary caregiver to children (yes, no); housing status (stably housed [rent/own], marginally housed or homeless [institution/street/single room occupancy hotel/homeless]); and health insurance status (insured, uninsured).

Clinical variables included self-reported health status (fair/poor, good/very good/excellent); domestic violence in current or last relationship (yes, no); time since HIV diagnosis (<1 year, 1–7 years, >7 years); self-reported diagnosis of depression (yes, no); and self-reported diagnosis of a medical comorbidity (e.g., hypertension, diabetes, arthritis) (any, none).

Risk behavior variables were current (within the last 3 months) high-risk drug use behaviors (cocaine, heroin, stimulant, or injection drugs), and high-risk sexual behaviors (sex with an injection drug user [IDU], transactional sex, unprotected sex with a male partner, or sex with an HIV-positive male partner).

Regarding structural barriers to HIV medical care, participants were asked to what extent each of the following affected their decision to get HIV medical care: inability to afford health care, housing or financial instability, transportation problems, inability to take time off school or work, and lack of child care. Potential responses were: "a little," "somewhat," or "a great deal." We categorized "a little" as "no" versus "somewhat" or "a great deal" as "yes".

Statistical analyses

To describe the overall sample and each of the three care status categories (in care, seekers, non-seekers), we calculated simple frequencies for the socio-demographic, clinical, and risk behavior variables and barriers. Next, using the traditional categorization, we examined differences between those in care versus out of care using bivariate and multivariate logistic regression, accounting for clustering by site. To contrast these traditional categorization findings with our nuanced categorization findings (in care, seekers, non-seekers),

we performed bivariate and multivariate multinomial logistic regression, accounting for clustering by site, to compare those women who are seekers or non-seekers with the reference category (in care), respectively. Odds ratios (OR) are presented with their corresponding 95% confidence intervals (CI). Independent variables which were significant at $p < 0.10$ in bivariate analyses were included in the final multivariate models. We forced age and race/ethnicity into the multivariate models as these have been consistently associated with engagement in HIV care in previous studies.^{6,17,22–25} All analyses were conducted using SAS statistical software (SAS 9.2, SAS Institute, Inc., Cary, NC).

Results

Sample characteristics

Of the 921 women enrolled, 173 were excluded from the analysis because 22 did not have complete data for our dependent variable of interest and 151 were recently diagnosed with HIV. Of the 748 women in our study sample, at the time of the baseline interview, 414 (55.3%) were in care, and 334 (44.7%) out of care. Of those out of care, 193 (25.8%) were seeking care (“seekers”) and 141 (18.9%) were not seeking care (“non-seekers”). Mean age for the overall sample was 41.8 ± 10.8 years old.

Most women were non-Hispanic black (65.6%), English speakers (86.8%), single (83.6%), had less than a high school education (58.0%), employed (83.0%), living in an urban area (69.5%), marginally housed or homeless (63.4%), and insured (72.3%) (Table 1). Almost half reported fair or poor health status (44.4%) and more than half (55.0%) had been diagnosed with HIV infection 7 or more years prior. Fourteen percent reported current drug use and almost one-third (30.5%) reported current high-risk sexual behaviors. Seventy-five percent reported at least one structural barrier to HIV medical care, specifically, 42.5% reported an inability to afford health care, 53.1% housing or financial instability, 55.2% transportation problems, 24.3% an inability to take time off school or work, and 15.0% lack of child care

Association between characteristics and barriers and care status using traditional categorization

In multivariate analysis using the traditional categorization of care status (in care versus out of care), those out of care were less likely to be black (OR = 0.65, 95% CI: 0.44–0.97), and more likely to be uninsured (OR = 1.68, 95% CI: 1.12–2.52), report fair or poor health status (OR = 1.45, 95% CI: 1.03–2.04), and report current high-risk drug use behaviors (OR = 1.87, 95% CI 1.16–2.99) (Table 2). There were no significant differences between the two groups in barriers to care.

Association between characteristics and barriers and care status using nuanced categorization

In multivariate analysis using our nuanced categorization of care status (in care, seekers, non-seekers), compared with women in care, seekers were more likely to be uninsured (OR = 1.63, 95% CI: 1.05–2.56) and to report fair or poor health status (OR = 1.54, 95% CI: 1.05–2.26) (Table 2). In contrast, in addition to being more likely to be uninsured (OR = 2.24, 95% CI: 1.22–4.12), non-seekers were more likely to report current high-risk drug use (OR = 3.93, 95% CI: 1.86–8.31) and sexual behaviors (OR = 1.95, 95% CI:

1.01–3.16), and were less likely to report transportation as a barrier (OR = 0.48, 95% CI: 0.26–0.89).

Discussion

Few published, rigorously tested interventions exist that are specifically focused on retaining HIV-positive women in medical care. To help inform the future development of targeted retention-in-care interventions for HIV-positive women, we sought to identify potential differences among women not engaged in care by taking into account care-seeking behaviors. By considering care-seeking behaviors, we identified important differences in characteristics between seekers (not engaged in care, but seeking care) and non-seekers (not engaged in care and *not* seeking care), differences that were not evident when the women were traditionally categorized as one homogenous group. When examined as a single group, women not engaged in care were less likely to be black and more likely to be uninsured, to report fair or poor health status, and report high-risk drug use behaviors. However, taking care-seeking behaviors into account revealed important distinctions among women not engaged in care. Compared to women in care, seekers were more likely to be uninsured and report fair or poor health status. In contrast, non-seekers were not only more likely to be uninsured, but to also report high-risk drug use and sexual behaviors and less likely to report transportation as a barrier to care.

Prior studies of women not engaged in HIV medical care have not explicitly examined potential differences among this group nor have they routinely taken into account role of care-seeking behaviors. Our findings suggest that among HIV-positive women who are not engaged in care, considering care-seeking behaviors uncovers key differences. Similar to previous studies, we found that regardless of care-seeking behaviors, women who are out of care were more likely to be uninsured.^{14,16–19} However, despite this finding, we found that, compared with women in care, both seekers and non-seekers were no more likely to perceive lack of health insurance as a barrier to care. Although prior studies have found drug use to be associated with poor engagement in care,^{14,16,19,21–25} we found that, compared with women in care, only non-seekers were more likely to report high-risk drug use and sexual behaviors. As this subgroup was less likely to report transportation as a barrier to care and was no more likely to report other structural barriers to care as women in care, our findings suggest that this subgroup of women may not report barriers because they are not actively seeking HIV medical care. Taken together, these findings indicate that women who are not engaged in care and *not* seeking care are a particularly vulnerable subgroup of HIV-positive women who are involved in high-risk behaviors and who may have limited to no interaction with the health care system.

Interventions focused on women who are not engaged in care and *not* seeking care may need to focus on risk behaviors, including drug use, and be community-based. As previously mentioned, substance use is a well-known factor associated with poor engagement in HIV care including among women. Effective interventions may need to incorporate substance use treatment or provide active referral to treatment programs. Efforts to engage women who are not seeking care must recognize that some women who are not engaged in care may not necessarily be actively seeking HIV

TABLE 1. SOCIO-DEMOGRAPHIC, CLINICAL, AND RISK BEHAVIOR CHARACTERISTICS AND BARRIERS TO HIV MEDICAL CARE FOR OVERALL SAMPLE AND BY CARE STATUS (N=748)

<i>Independent variable</i>	<i>Total sample (n = 748) n (%)</i>	<i>In care (n = 414) n (%)</i>	<i>Seekers (n = 193) n (%)</i>	<i>Non-seekers (n = 141) n (%)</i>
Age (years old)				
<30	117 (15.6%)	56 (13.5%)	24 (12.4%)	37 (26.2%)
30–50	463 (61.9%)	254 (61.4%)	128 (66.3%)	81 (57.5%)
>50	168 (22.5%)	104 (25.1%)	41 (21.2%)	23 (16.3%)
Race/ethnicity				
Hispanic	209 (27.9%)	106 (25.6%)	78 (40.4%)	25 (17.7%)
Non-Hispanic black	491 (65.6%)	278 (67.1%)	105 (54.4%)	108 (76.6%)
Other	46 (6.1%)	28 (6.8%)	10 (5.2%)	8 (5.7%)
Primary language				
English	649 (86.8%)	362 (87.4%)	158 (81.9%)	129 (91.5%)
Spanish	88 (11.8%)	47 (11.4%)	32 (16.6%)	9 (6.4%)
Other	11 (1.5%)	5 (1.2%)	3 (1.6%)	3 (2.1%)
Marital status				
Single	625 (83.6%)	351 (84.8%)	156 (80.8%)	118 (83.7%)
Married/partnered	123 (16.4%)	63 (15.2%)	37 (19.2%)	23 (16.3%)
Less than high school education	434 (58.0%)	249 (60.1%)	101 (52.3%)	84 (59.6%)
Unemployed	127 (17.0%)	62 (15.0%)	35 (18.1%)	30 (21.3%)
Living in a rural location	228 (30.5%)	98 (23.7%)	44 (22.8%)	86 (61.0%)
Primary caregiver	178 (23.8%)	101 (24.4%)	53 (27.5%)	24 (17.0%)
Marginally housed/homeless	474 (63.4%)	259 (62.6%)	121 (62.7%)	94 (66.7%)
Lack of health insurance (uninsured)	201 (26.9%)	83 (20.0%)	60 (31.0%)	58 (41.1%)
Fair or poor health status	332 (44.4%)	166 (40.1%)	100 (51.8%)	66 (46.8%)
Time since HIV diagnosis				
<1 year	87 (11.6%)	44 (10.6%)	17 (8.8%)	26 (18.4%)
1–7 years	250 (33.4%)	125 (30.2%)	76 (39.4%)	49 (34.8%)
>7 years	411 (55.0%)	245 (59.2%)	100 (51.8%)	66 (46.8%)
Domestic violence	220 (29.4%)	119 (28.7%)	54 (28.0%)	47 (33.3%)
Depression	33 (4.4%)	20 (4.8%)	8 (4.1%)	5 (3.5%)
Medical co-morbidity	232 (31.0%)	136 (32.9%)	71 (36.8%)	25 (17.7%)
Any current high-risk drug use behavior ^a	108 (14.4%)	52 (12.6%)	30 (15.5%)	26 (18.4%)
Cocaine	28 (3.7%)	14 (3.4%)	9 (4.7%)	5 (3.5%)
Heroin	92 (12.3%)	46 (11.1%)	22 (11.4%)	24 (17.0%)
Stimulants	9 (1.2%)	3 (0.7%)	3 (1.6%)	3 (2.1%)
IDU	14 (1.9%)	6 (1.4%)	6 (3.1%)	2 (1.4%)
Any current high-risk sexual behavior ^a	228 (30.5%)	106 (25.6%)	53 (27.5%)	69 (48.9%)
Sex with IDU	13 (1.7%)	8 (1.9%)	2 (1.0%)	3 (2.1%)
Transactional sex	43 (5.7%)	23 (5.6%)	11 (5.7%)	9 (6.4%)
Unprotected sex with male partner	175 (23.4%)	78 (18.8%)	41 (21.2%)	56 (39.7%)
Sex with HIV + male partner	72 (9.6%)	42 (10.1%)	13 (6.7%)	17 (12.1%)
Any structural barrier to HIV medical care	562 (75.1%)	319 (77.1%)	157 (81.4%)	86 (61.0%)
Inability to afford health care	318 (42.5%)	181 (43.7%)	89 (46.1%)	48 (34.0%)
Housing or financial instability	397 (53.1%)	229 (55.3%)	112 (58.0%)	56 (39.7%)
Transportation problems	413 (55.2%)	232 (56.0%)	126 (65.3%)	55 (39.0%)
Inability to take time off from work or school	182 (24.3%)	115 (27.8%)	43 (22.3%)	24 (17.0%)
Lack of child care	112 (15.0%)	71 (17.1%)	34 (17.6%)	7 (5.0%)

IDU, injection drug user.

^aCurrent means within the last 3 months.

medical care. As such, interventions targeting this subgroup may need to be based at venues or locales in which women who are not engaged in care and not seeking care may be more likely to frequent such as community-based organizations or homeless shelters. For instance, a recent systematic review identified few rigorously evaluated interventions focused on retention in care among HIV-positive individuals that were community-based and only two interventions that focused specifically on HIV-positive women, suggesting a

substantial need for community-based approaches to engaging women.³¹

As engagement in HIV care remains a persistent challenge, our findings underscore the importance of the research and public health communities taking into account the potential heterogeneity among those not engaged in care. Past studies that have treated those who are not engaged in care as one homogenous group may have missed important nuanced differences among subpopulations such as those observed in

TABLE 2. ASSOCIATION BETWEEN PARTICIPANT CHARACTERISTICS AND BARRIERS TO CARE AND CARE STATUS, COMPARING RESULTS FROM TRADITIONAL AND NUANCED CATEGORIZATION (N=748)

Independent variable	Traditional categorization ^a			Nuanced categorization ^b		
	Bivariate	Multivariate		Bivariate	Multivariate	
	Out of care vs. in care OR (95% CI)	Out of care vs. in care OR (95% CI)		Seekers vs. OR (95% CI)	Non-seekers vs. OR (95% CI)	Seekers vs. OR (95% CI)
Age						
< 30	1.03 (0.63–1.66)	1.44 (0.80–2.59)		0.99 (0.52–1.89)	1.77 (0.82–3.83)	1.22 (0.62–2.41)
30–50	0.82 (0.47–1.43)	1.24 (0.82–1.88)		1.24 (0.80–1.92)	1.31 (0.70–2.46)	1.16 (0.73–1.86)
> 50	ref	ref		ref	ref	ref
Race/ethnicity						
Hispanic	0.70 (0.47–1.02)	0.65 (0.44–0.97)	ref	ref	ref	ref
Non-Hispanic black	0.81 (0.39–1.65)	0.82 (0.39–1.73)		0.77 (0.44–1.35)	0.99 (0.35–3.83)	0.65 (0.42–1.00)
Other				0.70 (0.31–1.60)		0.84 (0.35–2.03)
Primary caregiver	1.09 (0.75–1.59)	–		1.17 (0.78–1.75)	0.49 (0.27–0.91)	1.37 (0.88–2.14)
Lack of health insurance	1.75 (1.18–2.60)	1.68 (1.12–2.52)		1.56 (1.01–2.39)	2.37 (1.35–4.15)	1.63 (1.05–2.56)
Fair/poor health status	1.48 (1.07–2.05)	1.45 (1.03–2.04)		1.61 (1.12–2.30)	1.07 (0.61–1.64)	1.54 (1.05–2.26)
Any current high risk drug use	2.08 (1.32–3.28)	1.87 (1.16–2.99)		1.46 (0.87–2.45)	4.48 (2.30–8.73)	1.44 (0.82–2.54)
Any current high risk sexual behavior	1.30 (0.91–1.86)	–		1.00 (0.67–1.49)	2.35 (1.42–3.89)	0.89 (0.57–1.39)
Inability to afford health care	0.83 (0.60–1.17)	–		0.97 (0.67–1.39)	0.61 (0.37–1.02)	–
Housing or financial instability	0.90 (0.65–1.26)	–		1.09 (0.75–1.58)	0.59 (0.36–0.96)	0.88 (0.57–1.35)
Transportation problems	1.04 (0.75–1.46)	–		1.41 (0.97–2.06)	0.52 (0.32–0.86)	1.41 (0.91–2.19)
Inability to take time off from work or school	0.68 (0.47–1.00)	0.68 (0.46–1.00)		0.76 (0.50–1.15)	0.55 (0.31–0.99)	0.70 (0.43–1.13)
Lack of child care	0.76 (0.49–1.20)	–		0.99 (0.61–1.58)	0.29 (0.12–0.73)	0.97 (0.56–1.67)

CI, confidence interval; OR, odds ratio; ref, reference category.

^aThe traditional categorization compares out of care versus in care.

^bNuanced categorization compares seekers versus in care and non-seekers versus in care.

The reference group is “in care” for both logistic (traditional categorization) and multinomial (nuanced categorization) regression analyses.

Seekers vs. in care and non-seeker vs. in care comparisons were calculated using one multinomial logistic regression model in bivariate analysis and a separate model for multivariate analysis. Blank (-) cells indicate that the variable was not significant at $p < 0.10$ level in bivariate analyses and, therefore, was not included in final multivariate models. Any current high risk drug use is defined as cocaine, heroin, injection drug, or stimulant use in last 3 months. Any current high risk sexual behavior is defined as transactional sex, sex with an IDU, unprotected sex with a male partner or sex with HIV + male partner in the last 3 months.

our study. Understanding key differences among distinct subgroups can guide development of targeted interventions that aim to improve engagement in care for vulnerable subgroups, thus, filling the existing void of rigorously evaluated interventions to promote engagement in care.

Our study has several limitations. First, one eligibility criterion focused on previous clinical visits at only one specific site. As such, it is possible that some participants may have been engaged in care at another clinical site and therefore, could have been misclassified in our analyses. Second, our categorization of care status and care-seeking behavior relied on self-report. Therefore, assessment of receipt of medical care could have been inaccurate. Third, we dichotomized care-seeking behavior, a health behavior which is complex and dynamic.^{32–34} Yet, we believe this analysis serves as a formative step to begin investigating novel ways of thinking about engagement in care that can reveal important distinctions. Fourth, diagnoses of mental health and co-morbid medical conditions were based on participant self-report and, as such, may have been under-reported. Therefore, we are unable to fully explore their contributions to our findings. Lastly, we did not have access to participants' CD4 cell count and HIV viral load data at the time of enrollment. Consequently, we were unable to determine to what extent there may have been differences in immunologic and virologic control between groups and how these variables might be associated with care status.

In a multisite study of HIV-positive women, we found that women who are not engaged in HIV medical care are a heterogeneous group. Specifically, compared to women in care, women who were not engaged in care and *not* seeking care were more likely to be uninsured and report current high-risk behaviors and less likely to report transportation as a barrier. Our findings suggest that a single, uniform approach to women who are not engaged in HIV medical care will likely be insufficient given the heterogeneity in key characteristics, particularly risk behaviors, among women not engaged in care. Moreover, they highlight the need for those developing targeted interventions to think creatively about how to engage HIV-positive women who may have limited interaction with health care system and are at high risk for poor health outcomes.

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References

1. Aziz M, Smith KY. Challenges and successes in linking HIV-infected women to care in the United States. *Clin Infect Dis* 2011;52:S231–S237.
2. Hader SL, Smith DK, Moore JS, Holmberg SD. HIV infection in women in the United States: Status at the millennium. *JAMA* 2001;285:1186–1192.
3. Centers for Disease Control and Prevention (CDC). HIV in the United States: The stages of care. Available at: http://www.cdc.gov/hiv/pdf/research_mmp_StagesofCare.pdf (Last accessed September 5, 2014).
4. Mugavero MJ, Lin HY, Willig JH, et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. *Clin Infect Dis* 2009;48:248–256.
5. Giordano TP, Gifford AL, White AC, Jr, et al. Retention in care: A challenge to survival with HIV infection. *Clin Infect Dis* 2007;44:1493–1499.
6. Horberg MA, Hurley LB, Silverberg MJ, et al. Missed office visits and risk of mortality among HIV-infected subjects in a large healthcare system in the United States. *AIDS Patient Care STDS* 2013;27:442–449.
7. Crawford TN, Sanderson WT, Thornton A. Impact of poor retention in HIV medical care on time to viral load suppression. *J Int Assoc Provid AIDS Care* 2014;13:242–249.
8. Wood E, Hogg RS, Yip B, et al. Effect of medication adherence on survival of HIV-infected adults who start highly active antiretroviral therapy when the CD4 cell count is 0.200 to 0.350 × 10⁹ cells/L. *Ann Intern Med* 2003;139:810–816.
9. Bangsberg DR, Perry S, Charlebois ED, et al. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. *AIDS* 2001;15:1181–1183.
10. Attia S, Egger M, Muller M, et al. Sexual transmission of HIV according to viral load and antiretroviral therapy: Systematic review and meta-analysis. *AIDS* 2009;23:1397–1404.
11. Kempf M, McLeod J, Boehme AK, et al. A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern United States: Implications for targeted interventions. *AIDS Patient Care STDS* 2010;24:515–520.
12. Moneyham L, McLeod J, Boehme A, et al. Perceived barriers to HIV care among HIV-infected women in the deep south. *J Assoc Nurses AIDS Care* 2010;21:467–477.
13. Messer LC, Quinlivan EB, Parnell H, et al. Barriers and facilitators to testing, treatment entry, and engagement in care by HIV-positive women of color. *AIDS Patient Care STDS* 2013;27:398–407.
14. Palacio H, Shiboski CH, Yelin EH, et al. Access to and utilization of primary care services among HIV-infected women. *J Acquir Immune Defic Syndr* 1999;21:293–300.
15. Lillie-Blanton M, Brodie M, Rowland D, et al. Race, ethnicity, and the health care system: Public perceptions and experiences. *Med Care Res Rev* 2000;57:218–235.
16. Cunningham C, Buck J, Shaw FL, et al. Factors associated with returning to HIV care after a gap in care in New York State. *J Acquir Immune Defic Syndr* 2014;66:419–427.
17. Hu YW, Kinsler JJ, Sheng Z, et al. Using laboratory surveillance data to estimate engagement in care among persons living with HIV in Los Angeles county, 2009. *AIDS Patient Care STDS* 2012;26:471–478.
18. Mugavero MJ, Lin HY, Allison JJ, et al. Failure to establish HIV care: Characterizing the “no show” phenomenon. *Clin Infect Dis* 2007;45:127–130.

19. Naar-King S, Bradford J, Coleman S, et al. Retention in care of persons newly diagnosed with HIV: Outcomes of the outreach initiative. *AIDS Patient Care STDS* 2007;21: S40–S48.
20. Stein MD, Crystal S, Cunningham WE, et al. Delays in seeking HIV care due to competing caregiver responsibilities. *Am J Public Health* 2000;90:1138–1140.
21. Pecoraro A, Royer-Malvestuto C, Rosenwasser B, et al. Factors contributing to dropping out from and returning to HIV treatment in an inner city primary care HIV clinic in the United States. *AIDS Care* 2013;25:1399–1406.
22. Rebeiro P, Althoff KN, Buchacz K, et al. Retention among North American HIV-infected persons in clinical care, 2000–2008. *J Acquir Immune Defic Syndr* 2013;62:356–362.
23. Marx KA, Malka ES, Ravishankar J, Schwartz RM. Measurement of retention in care among adults infected with HIV in an urban clinic. *AIDS Care* 2011;23:1298–1304.
24. Torian LV, Wiewel EW. Continuity of HIV-related medical care, New York City, 2005–2009: Do patients who initiate care stay in care? *AIDS Patient Care STDS* 2011;25: 79–88.
25. Ulett KB, Willig JH, Lin H, et al. The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care STDS* 2009;23:41–49.
26. Andersen RM. Revisiting the behavioral model and access to medical care: Does it matter? *J Health Soc Behav* 1995: 1–10.
27. Andersen M, Hockman E, Smereck G, et al. Retaining women in HIV medical care. *J Assoc Nurses AIDS Care* 2007;18:33–41.
28. Eastwood EB, Fletcher J, Quinlivan EB, et al. Baseline social characteristics and barriers from a Special Projects of National Significance Women of Color with HIV study: A comparison of urban and rural women and barriers to HIV care. *AIDS Patient Care STDS* 2015;29(Suppl 1):S4–S10.
29. University of San Francisco Center for AIDS Prevention Studies. EPPEC cross site evaluation patient assessment. Available at: <http://caps.ucsf.edu/uploads/tools/surveys/pdf/EPPEC-PatientAssessment.pdf> (Last accessed September 5, 2014).
30. Smith PH, Earp JA, DeVellis R. Measuring battering: Development of the women's experience with battering (WEB) scale. *Womens Health* 1995;1:273–288.
31. Higa DH, Marks G, Crepaz N, et al. Interventions to improve retention in HIV primary care: A systematic review of US studies. *Curr HIV/AIDS Rep* 2012;9:313–325.
32. Beer L, Fagan JL, Valverde E, Bertolli J. Health-related beliefs and decisions about accessing HIV medical care among HIV-infected persons who are not receiving care. *AIDS Patient Care STDS* 2009;23:785–792.
33. Rajabiun S, Mallinson RK, McCoy K, et al. “Getting me back on track”: The role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. *AIDS Patient Care STDS* 2007;21:S20–S29.
34. Raveis V, Siegel K, Gorey E. Factors associated with HIV-infected women's delay in seeking medical care. *AIDS Care* 1998;10:549–562.

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